THE BETTER THE PATIENT/HUMAN EXPERIENCE =
THE MORE ENGAGED PATIENTS/FAMILIES =
THE BETTER THE OUTCOMES ARE!

Introduction



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Background:

- CI user
- 25+ years leading patient programs in healthcare & biopharma
- 20+ years board service for DHH organizations
- Certified Patient Experience Professional (CPXP)
- Certified Professional Patient Advocate in Life Sciences (PPALS)

Disclaimer

The views and opinions expressed in the following presentation are those of the individual presenter and should not be attributed to any organization with which the presenter is employed or affiliated. This presentation is completely separate and unrelated to my role as exhibitor in the hall.

Agenda

- What is Patient Experience (PX)?
- Why Patient Experience?
- My CI experience
- Sarah’s CI experience
- Key Takeaways

What is Patient Experience (PX)?



Why: The clinical case for optimal PX

- PX positively correlates to processes of care for both prevention and condition management.
  - For example, diabetic patients demonstrate greater self-management skills and quality of life when they report positive interactions with their providers.
- Patients' experiences with care, particularly communication with providers, correlate with adherence to medical advice and treatment plans.
  - This is especially true among patients with chronic conditions, where a strong commitment from patients to work with their providers is essential for achieving positive results.
- Patients with better PX often have better health outcomes.
  - For example, studies of patients hospitalized for heart attack showed that patients with more positive reports about their experiences with care had better health outcomes a year after discharge.

Same applies for cochlear implant candidates, users, and families!!!

Source: Why Improve Patient Experience? | Agency for Healthcare Research and Quality (ahrq.gov)

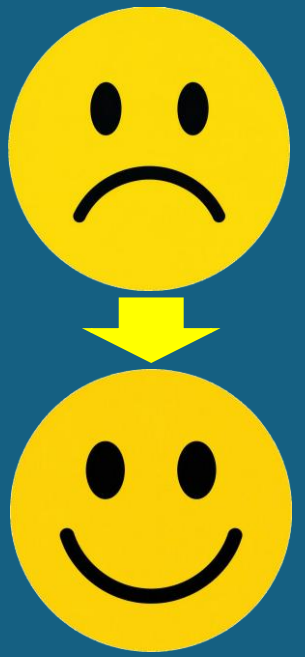
My patient experience

- Grew up profoundly deaf.
- Used hearing aids.
- At age 28 - went to a renowned CI center based on recommendations from others whom I trust. I was told I'd have a series of appointments:
  1. CI center Director – walked me through my schedule for half day
  2. Audiologist – for testing in booth and discussion re CI options
  3. CI surgeon – for exam, consultation, and Q&A
  4. Psychologist – to ensure expectations were managed
- In all:
  - An incredibly seamless, cohesive team effort
  - Excellent communications by all
  - Was presented with all CI options – but would not advise which one to get!
    - Had to do my own research and select based on my own priorities/preferences.
    - Team happily addressed all questions I had.
- Came back for surgery. All went well and went home same day.
- And came back for follow-up mappings, which went well.



Sarah's patient experience

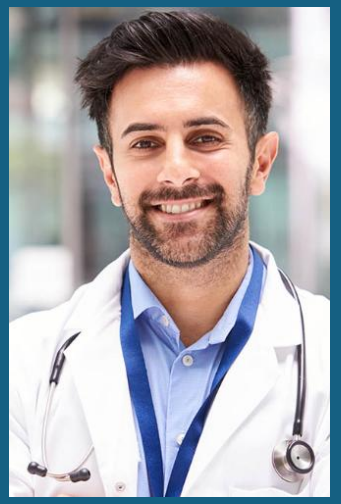
- Born hearing, but experienced moderate to severe hearing loss in one ear and profound in other ear at age 2. Wore hearing aid in better ear.
- Lost remaining hearing in other ear at age 29 just months before starting grad school
- Went to another renowned "Ear hospital" for hearing loss, but only got appointment with CI surgeon who told her:
  - Had to go here and there to schedule varying appointments here and there whenever they have a slot available.
  - She couldn't get surgery before starting grad school
  - She could only get one CI brand – not a choice
- Called my CI surgeon to recommend another CI Center nearby. He recommended his protégé at a much lesser-known facility
- Had the best experience.



How do you think we filled out the patient satisfaction survey?

CARE PROVIDER	very poor 1	poor 2	fair 3	good 4	very good 5
PLEASE ANSWER THE FOLLOWING QUESTIONS WITH THAT HEALTH CARE PROVIDER IN MIND.					
1. Concern the care provider showed for your questions or worries	O	O	O	O	O
2. Explanations the care provider gave you about your problem or condition	O	O	O	O	O
3. Care provider's efforts to include you in decisions about your care	O	O	O	O	O
4. Care provider's discussion of any proposed treatment (options, risks, benefits, etc.)	O	O	O	O	O
5. Likelihood of your recommending this care provider to others	O	O	O	O	O

Advocate for accountability



Michael A. Burke, MD

Reviews

★★★★★ **5 of 5 stars** 229 Ratings, 57 Reviews

Likelihood of recommending to others	★★★★★ 5
Your confidence in care provider	★★★★★ 5
Explanations about your problem/condition	★★★★★ 5
Concern shown for your questions/worries	★★★★★ 5
Efforts made to include you in treatment decisions	★★★★★ 5
CP discuss treatments	★★★★★ 5

★★★★★ 5 of 5 stars

The way Dr. Burke prepares for the visit in advance is extraordinary.

★★★★★ 5 of 5 stars

Dr. Burke shows the utmost concern for my care. He is an amazing doctor.

Note: This is a fictional doctor and set of ratings and comments for illustrative purposes.

Key Takeaways

- Patient Experience = all perceptions and interactions across the continuum of own care
- Optimal patient experience = strong patient engagement
- Strong patient engagement = strong health outcomes, including ability to hear as well as possible with cochlear implants.
- Empower yourself and others (if and however possible) to find the right CI care providers – via word of mouth, online reviews, etc.
  - Continue to advocate for person-centered services to ensure optimal experience and outcomes

The last word!



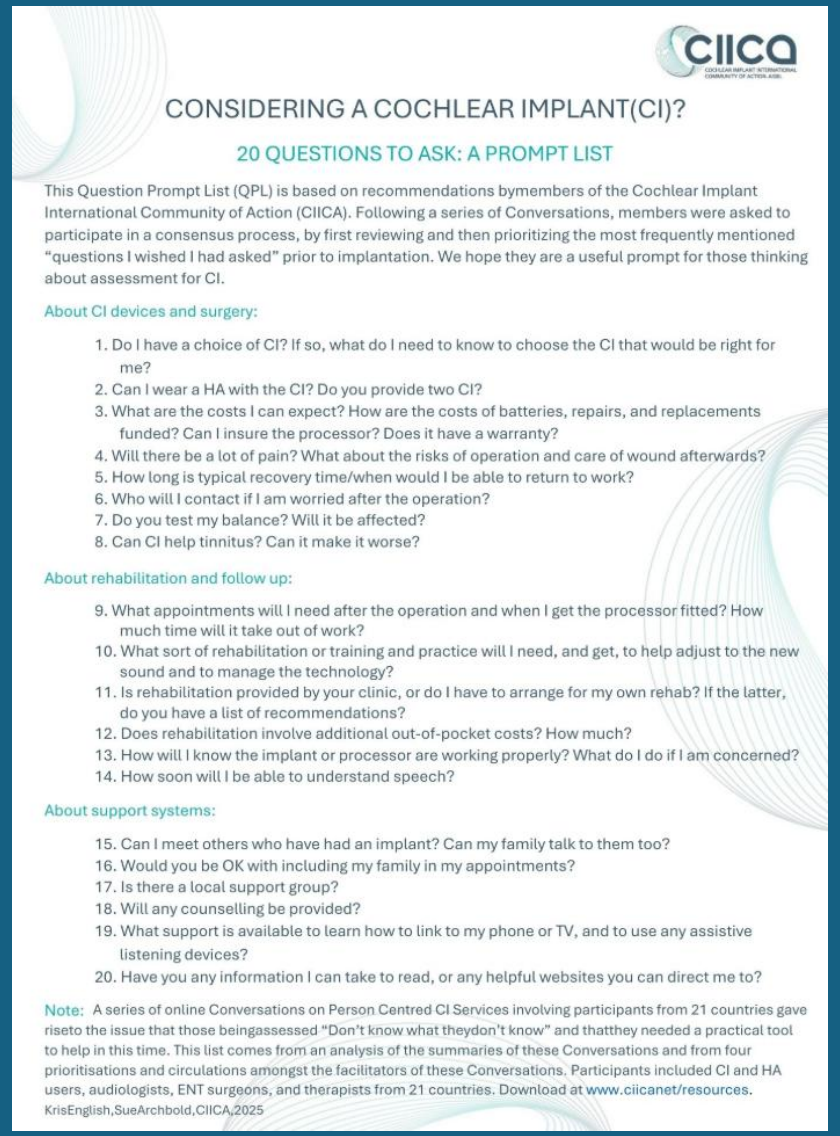
“It is so important that CI users have personalized and ongoing sustainable support from their professional teams to ensure that these recognized benefits (of cochlear implants) are realized.”

What’s your experience?!

- Does your CI center provide good patient experience?
- How much does your CI team impact your own CI experience?
- What did/do they do well and not so well?
- What can they do better?

Consider using 20 Questions Prompt List

- Using tools like this can help you
  - Get answers you need for best experience, care, and decision-making purposes
  - Assess clinical team to determine whether to go with them or another one (if able to shop around)



CIICA

CONSIDERING A COCHLEAR IMPLANT(CI)?

20 QUESTIONS TO ASK: A PROMPT LIST

This Question Prompt List (QPL) is based on recommendations bymembers of the Cochlear Implant International Community of Action (CIICA). Following a series of Conversations, members were asked to participate in a consensus process, by first reviewing and then prioritizing the most frequently mentioned "questions I wished I had asked" prior to implantation. We hope they are a useful prompt for those thinking about assessment for CI.

About CI devices and surgery:

1. Do I have a choice of CI? If so, what do I need to know to choose the CI that would be right for me?
2. Can I wear a HA with the CI? Do you provide two CI?
3. What are the costs I can expect? How are the costs of batteries, repairs, and replacements funded? Can I insure the processor? Does it have a warranty?
4. Will there be a lot of pain? What about the risks of operation and care of wound afterwards?
5. How long is typical recovery time/when would I be able to return to work?
6. Who will I contact if I am worried after the operation?
7. Do you test my balance? Will it be affected?
8. Can CI help tinnitus? Can it make it worse?

About rehabilitation and follow up:

9. What appointments will I need after the operation and when I get the processor fitted? How much time will it take out of work?
10. What sort of rehabilitation or training and practice will I need, and get, to help adjust to the new sound and to manage the technology?
11. Is rehabilitation provided by your clinic, or do I have to arrange for my own rehab? If the latter, do you have a list of recommendations?
12. Does rehabilitation involve additional out-of-pocket costs? How much?
13. How will I know the implant or processor are working properly? What do I do if I am concerned?
14. How soon will I be able to understand speech?

About support systems:

15. Can I meet others who have had an implant? Can my family talk to them too?
16. Would you be OK with including my family in my appointments?
17. Is there a local support group?
18. Will any counselling be provided?
19. What support is available to learn how to link to my phone or TV, and to use any assistive listening devices?
20. Have you any information I can take to read, or any helpful websites you can direct me to?

Note: A series of online Conversations on Person Centred CI Services involving participants from 21 countries gave riseto the issue that those beingassessed "Don't know what theydon't know" and thatthey needed a practical tool to help in this time. This list comes from an analysis of the summaries of these Conversations and from four prioritisations and circulations amongst the facilitators of these Conversations. Participants included CI and HA users, audiologists, ENT surgeons, and therapists from 21 countries. Download at www.ciicanet/resources.

KrisEnglish,SueArchbold,CIICA,2025